



KIM HIXSON

STATE REPRESENTATIVE • WISCONSIN LEGISLATURE • 43RD ASSEMBLY DISTRICT

Serving Rock, Walworth, Jefferson and Dane Counties

REPRESENTATIVE HIXSON TESTIMONY ON SENATE BILL 3

Good Morning. Chairman Carpenter, members of the committee, thank you for the opportunity to appear before your committee this morning in support of Senate Bill 3, which would extend insurance coverage to families who have children with autism.

Before I speak about the merits of this legislation, I would also like to recognize all of the families here today, who have worked so hard to bring this important legislation to this point today. These families have shown what good hard-working people, who love their children and want the best for them, can accomplish. These families like so many other families across the State of Wisconsin and our nation, face joys and challenges in caring for an autistic child *every* day, the likes of which we can only imagine. And thanks to their hard work we have a very strong bill, which with your help can finally be signed into law.

Even though Autism is a disease almost like any other, many insurance companies refuse to provide coverage. In order to get treatment for their child, many families must *pay right out of their pocket* – sometimes sacrificing their home, their hopes and their dreams. As Sen. Robson mentioned, as many as a half-million Americans under the age of 21 have autism. That's about 1 in every 150 children who are affected by this disease. Maybe you know one of those affected.

We need to make sure that the struggles of families touched by autism do not include financial worries as well. This legislation would provide relief to not only those families with autism, but to all of society. By diagnosing and treating autism early, these children and families will be able to succeed with no limitations. It will also help us keep costs down to taxpayers in the long-term by these children having less need for support services later in life.

This legislation differs from the version introduced last session in three key ways:

- It includes minimum coverage levels for intensive and post-intensive treatment at \$60,000 and \$30,000, respectively of 30-35 hours per week for at least four years;
- It includes speech, language and occupational therapy coverage;
- And, it provides for the reduction of coverage – only when it is determined that less coverage is medically appropriate.

Insurance companies spend a lot of money on advertising and marketing to assure us that we are “in good hands” or that they are just “like a good neighbor” and will be there when we need help. But when parents struggle to find help for a child with autism, many insurance companies are nowhere to be found. At least 18 other states now require insurance companies to do what is right and cover autism spectrum disorders. Wisconsin should join them. Thank you for the opportunity to come and speak with you about this important legislation. I urge you to support SB-3. These families need our support.



State of Wisconsin
Department of Health Services

Jim Doyle, Governor
Karen E. Timberlake, Secretary

Testimony of Secretary Karen Timberlake
Senate Committee on Public Health, Senior Issues, Long-Term Care and Job Creation
February 9, 2009

Good morning Chairman Carpenter and members of the Committee. Thank you for inviting me and thank you for taking up this important legislation.

A similar version of this bill was included in Governor Doyle's biennial budget during the 2007-08 session and was approved by the full Senate. Governor Doyle and we at the Department of Health Services appreciate the past support of the Senate for this important legislation. We are optimistic that this bill will be passed into law and will make treatment for autism spectrum disorders accessible and affordable for more Wisconsin families.

What is Autism?

Autism is a developmental disorder defined by symptoms, appearing before the age of three, which reflect delayed or abnormal development in three areas: language development, social skills, and restricted and repetitive behavior.

The severity of these developmental delays varies widely from child to child. The three most typical diagnoses are autism, Asperger's syndrome, and pervasive developmental disorder not otherwise specified. This range of diagnoses makes up the "autism spectrum." The level and type of treatment needed is directly related to where the child falls along the spectrum.

In recent years the rate of autism spectrum diagnoses has skyrocketed. Currently, 1 out of every 150 children is diagnosed somewhere on the autism spectrum, compared to 4 out of every 10,000 just two decades ago.

Fortunately, the outlook for children with an autism spectrum disorder is better now than ever before. Before the 1990's, children with autism did not receive much help and many of them did not get much better. Now, research – much of it done right here in Wisconsin – shows that with proper treatment, about half of even the more severely affected children can improve enough to succeed in school and live in many respects as typical children do.

During the toddler and preschool years, children are able to learn rapidly. For this reason, children with social and language delays show much greater improvement if they begin treatment before age five and receive intensive treatment (35 to 40 hours per week) during their first few years of life.

Children's Long Term Support Waivers and Autism

Treatment for autism spectrum disorders is very expensive. The State, through the Children's Long-Term Support Medicaid Home and Community-Based Services Waivers, has provided funding for treatment services for children with autism spectrum disorders since 2004. These waivers were reauthorized for 5 years in November 2006, and the State follows a 5-year renewal cycle.

Children in the intensive component of the current waiver program receive one-on-one behavioral treatment only. No other non-treatment services are authorized for children in the intensive phase of the program. Children enrolled in the on-going autism waiver program may continue to pursue behavioral treatment, although fewer hours of treatment are covered. They may also receive other therapy and supportive services intended to sustain and maximize gains made during intensive-level treatment.

As of January 1, 2009, there were 695 children receiving intensive in-home treatment services and 1,276 receiving ongoing treatment and community services under the waivers. There were 335 children waiting for autism services due to funding limitations. It is estimated that children beginning to be served as of January 1, 2009 have waited approximately 12 - 18 months for waiver funding, including the time spent attaining a diagnosis and determining eligibility.

In the year or more that these children wait for an opening in the waiver program, their parents are faced with a difficult choice: spend thousands – frequently tens-of-thousands – of dollars out of their own pockets to pay for treatment, or wait and hope their child doesn't fall further behind. Reports of families selling their homes, taking out second mortgages, taking on second and third jobs, are all too familiar to anyone who has interacted with a family with a child on the autism spectrum.

If SB 3 becomes law, the Department of Health Services estimates that requiring insurers to cover treatment services for autism treatment will allow approximately one-third of the children currently eligible for the waiver program but on the waiting list to access the same level of services through their private insurance.

In addition, a significant number of children currently in the state waiver program will be able to access the same level of care through private insurance. We estimate that 34% of children in the "intensive treatment" program and 11% in the "post intensive" treatment program will be able to access private insurance under SB 3. This will open up additional slots in the waiver program to serve families on the wait list who cannot access private insurance.

With families transitioning from the waiver program and the waiting list to private insurance, we estimate that the entire waiting list will be eliminated by 2011.

Transitioning Children from the Waivers to Insurance Coverage

Passage of SB 3 will require families who are currently being served by the waiver program to transition to private insurance coverage if it is available to them. We understand that many parents currently in the waiver program may wish to stay in the program; however, federal regulations require that Medicaid is the payer of last resort, including Medicaid waiver programs. Families with private insurance that meets the provisions of SB 3 will not be able to access the waiver program.

Children will not be abruptly cut off from the waiver program once SB 3 is signed into law. Children who are eligible for waiver services will continue to receive those services until it has been determined that they have insurance that will fund the service.

DHS will work with local waiver agencies to help identify those waiver participants who may have health insurance. DHS will work with local waiver staff and families to design a plan that assures continuity of service and a smooth transition to treatment covered by insurance. We will develop informational materials that will be distributed to local waiver agencies so that waiver agency staff can help families and their providers smoothly coordinate the process of accessing available insurance coverage for services provided.

SB 3 represents a long-term solution to the problem of the waiver waiting list. Passage of this bill will allow children to access treatment as soon as possible. Autism is a condition that cannot be cured but can be treated successfully. Early diagnosis and treatment are vital. SB 3 will allow families more options to access early, intensive treatment and will improve the future of hundreds of Wisconsin's children.



State of Wisconsin / OFFICE OF THE COMMISSIONER OF INSURANCE

Jim Doyle, Governor
Sean Dilweg, Commissioner

Wisconsin.gov

125 South Webster Street • P.O. Box 7873
Madison, Wisconsin 53707-7873
Phone: (608) 266-3585 • Fax: (608) 266-9935
E-Mail: ociinformation@wisconsin.gov
Web Address: oci.wi.gov

**Testimony of Commissioner Sean Dilweg
To the Senate Committee on Public Health, Senior Issues, Long-Term Care, and
Job Creation
SSA 1 to SB 3
February 9, 2009**

Chairman Carpenter and Members of the Committee:

Thank you for the opportunity to testify today in support of Senate Substitute Amendment 1 to Senate Bill 3, relating to health insurance coverage of treatment for autism spectrum disorders.

Senate Substitute Amendment 1 goes a long way in ensuring individuals diagnosed with autism get the treatment services they need. Most notably:

- Treatment services must be prescribed by a physician.
 - This ensures a licensed medical professional has assessed an individual's condition and is prescribing necessary treatment.
- Insurers must cover at least \$60,000 for intensive-level services per year with a minimum of 30 to 35 hours of care per week for at least 4 years. \$30,000 in coverage must be provided for post-intensive level treatment.
 - This language reflects the true cost of intensive and post-intensive level services and provides a clear indication to insurers of the expected coverage levels.
- Broad definitions of intensive and post-intensive level treatment are included in the bill with the direction that the Insurance Commissioner further define them.
 - Should this bill pass, I am committed to bringing interested parties to the table in an effort to build consensus around what will specifically be categorized as intensive and post-intensive level treatment.
- Coverage may not be subject to limitations or exclusions, including the limitations on the number of treatment visits.
 - The addition of this language is important to ensure there is a clear indication to insurers that coverage not be limited. Limiting, for example, the number of visits a child can receive from any one of his or

her treatment providers could be detrimental to their progress under a treatment plan.

Financial Impact

Last session my office prepared a social and financial impact statement for SB 178 which also mandated health insurance coverage of autism treatment services in the same manner as SB 3. With a focus on intensive therapies, it was estimated the mandate would cost the private insurance industry in Wisconsin approximately \$20.4 million annually. This is in relation to the approximately \$8 billion in health insurance premium collected by insurers annually in this state. When considering the 1.6 million privately insured Wisconsin residents, it is estimated the mandate will cost \$1.06 per privately insured person, per month (pm/pm).

In looking at experience in other states, I was able to obtain data from Aetna in 2007 indicating that company experienced only a \$0.007 pm/pm cost when covering services under the New Jersey mandate and \$0.004 pm/pm when covering services in Connecticut. Both mandates related to autism coverage in those states falls under the state's mental health parity laws.

Conclusion

Time is of the essence for children with autism. The key to successful intensive treatment is ensuring children receive it within the first few years of life and immediately after diagnosis. Private insurance coverage is the right thing to do to ensure kids, like those in this room today, have access to services that can afford them an opportunity toward improved cognitive and physical development. Assuming improved outcomes resulting from early access to treatment, SSA 1 to SB 3 will not only lead to improved quality of life for children with Autism but will likely lead to future cost savings in the areas of special education services, medical needs, long term care support and lost productivity of people with ASD and their parents.

Thank you Chairman Carpenter and members of the Committee for your consideration of these changes.



KEVIN PETERSEN

STATE REPRESENTATIVE

Thank-you Chairman Carpenter and other members of the Senate committee on Public Health, Senior Issues, Long-Term Care, and Job Creation for hearing my testimony today on Senate Bill 3 – The Autism Insurance Mandate.

The Lord has blessed my wife and myself with two beautiful daughters sitting with me today – Nicole age 11 and Kaylee age 9. Both daughters diagnosed autistic pervasive developmental disorder not otherwise specified (PDD – NOS).

Our lives are just like the lives of all the other families at this hearing and throughout the state of Wisconsin with autistic children. It is a daily roller coaster of challenges and emotions.

As a legislator with autistic children I am able to both relate with the autism challenges and emotions as well as the legislative bureaucracy involved with this bill. What has to be remembered is when we vote on the floor, we don't vote on emotions, press releases, or news media hype, we vote on the words as they are stated in the bill. For it is the words printed in the actual bill that become law.

It is for that reason I find Senate Bill 3 – the Autism Insurance Mandate - has three major flaws when addressing the needs of autistic children and their families.

First, read the analysis by the Legislative Reference Bureau for the Autism Insurance Mandate bill, Sentence one: "This bill requires health insurance policies and self-insured governmental and school district health plans to cover the cost of treatment for an insured for autism ..."

Noticeably exempt from those words are "self insured private business." Nearly 50% of all Wisconsin residents get their insurance through their employers who self-fund their health insurance plans. These plans are regulated by federal law (Employee Retirement Income Security Act [ERISA]) and are exempt from all state mandates.

Approximately 20% of Wisconsin residents are in government programs, like Medicare, which are also exempt from state mandates. Furthermore, the bill can

only apply to Wisconsin employers, so if you live in Hudson, Prairie du Chien, or Hurley and cross the border to work at a job in Minnesota, Iowa, or Michigan, your autistic child would not be covered by the mandate either.

In a memo to my office dated January 13, 2009, from the non-partisan Legislative Fiscal Bureau, these numbers are confirmed. The memo states: "The Wisconsin Office of the Commissioner of Insurance (OCI) estimates that approximately 29% of Wisconsin's population has health insurance coverage to which the state insurance coverage mandates directly apply."

Even Governor Doyle's press release dated February 3, 2009 confirms this fact. The last sentence in the second to last paragraph states: "By passing this bill, the current waiting list for autism treatment can be cut by one-third, providing more kids access to the services they deserve sooner."

In other words, less than one in three autistic children in Wisconsin would get their intensive in home therapy paid for by insurance under the Senate's autism insurance mandate.

Secondly, per the non-partisan Legislative Fiscal Bureau's estimate attached to this bill: "This bill requires all health insurance plans offered by the Group Insurance Board (GIB) under Chapter 40 of the Wisconsin State Statutes to provide coverage for Autism Syndrome Disorder (ASD) which includes Autism, Asperger's syndrome and Pervasive Development Disorder not otherwise specified."

According to the Government Insurance Board's consulting actuary, the estimated cost of insurance premiums for this bill would range from \$7.4 million to \$8.7 million dollars annually for state employees. Additionally, the annual cost for plans offered to local government employees would range from \$1.4 million to \$1.6 million.

I want you and everyone in this room and in the State of Wisconsin to realize that if legislators vote "yes" for the Autism Insurance Mandate, they are voting to spend over \$10 million dollars per year of taxpayer money to ensure kids of government employee's including themselves are 100% covered for autism services while leaving 2/3 of the state's population uncovered by such mandate.

Rather than spending an additional \$10 million tax dollars on state employee and local government healthcare premiums to cover only 1/3 of the state's autistic children, we can spend less than \$6 million dollars fully funding the autism waiver program to eliminate the waiting list completely. Many of you are aware that last session, Representative Newcomer (another parent of an autistic child) and I brought just such a proposal forward. We will be bringing this proposal forward again this session.

Thirdly, there is no funding mechanism guarantee in Senate Bill 3 - the Autism Insurance Mandate - that would ensure the 2/3's of the children not covered would have access to state assistance.

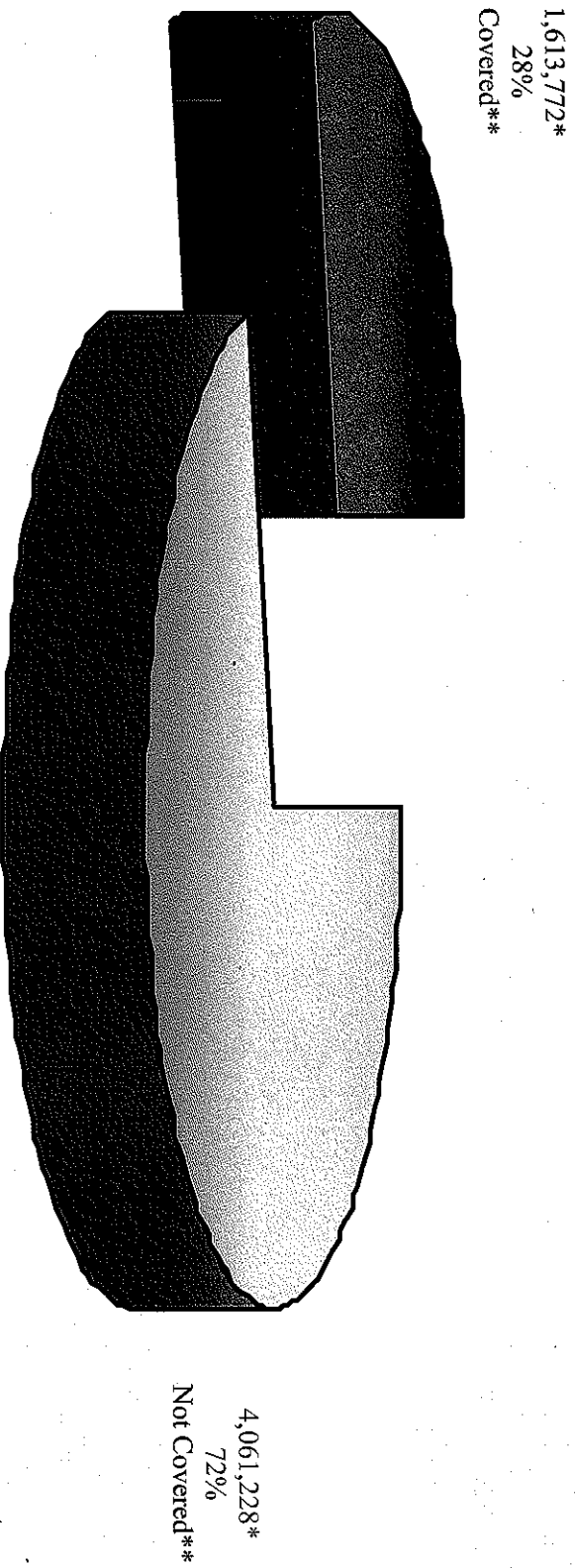
Under 2007 Wisconsin Act 20 (the 2007-09 biennial budget act) approximately \$83 million dollars is budgeted to support autism treatment services. Of that \$83 million, \$34 million is Wisconsin General Purpose Revenue and \$49 million is Federal matching funds.

We can not forget that in 2003, Governor Doyle's first budget proposed to eliminate state funds for intensive in-home care for autism. There are no safe guards in this bill which would keep him or other legislators from raiding or eliminating the state's current financial commitment to autism in the next biennial budget. Because of the Autism Insurance Mandate's exclusion of 2/3 of Wisconsin's autistic children, a decrease in funding could effectively increase the state's waiting list for the autism waiver program.

I find it unfathomable that legislators under the Capitol dome in Madison - both the Senate and the Assembly - would prey on the emotions of families like mine throughout the state with autism, and give them false hope that an insurance mandate only covering 29% of the autistic kids in this state is satisfactory.

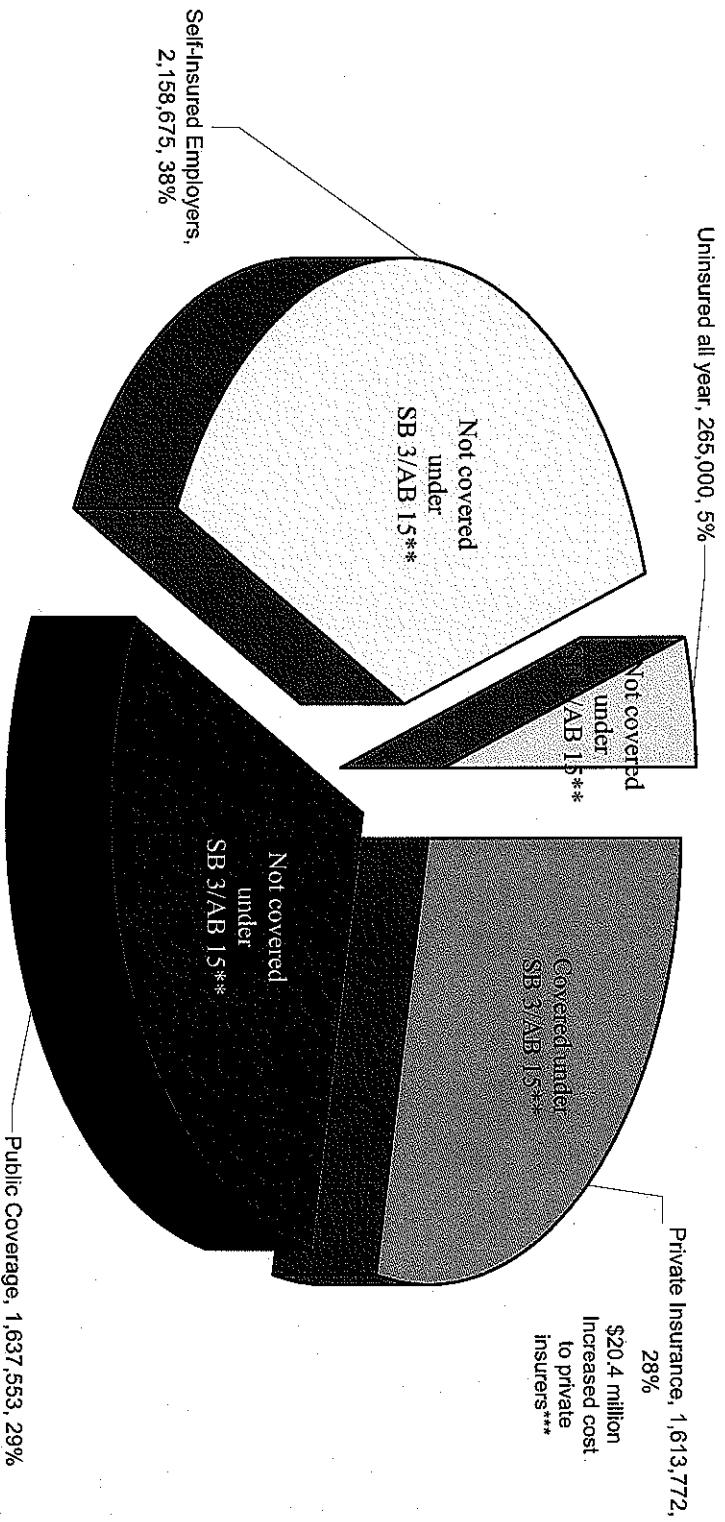
There's a big difference between a political answer and a real solution. The last thing autistic children and their families need are 1/3 measures. The parents of autistic children have told us what their children need. Now, let's work together to ensure that 100% of autistic children receive the service they so vitally require.

Coverage Under a Mandate



* Office of the Commissioner of Insurance memo, June 6, 2008 and 2007 graph
** Legislative Fiscal Bureau memo, January 13, 2009 SB3/AB 15 coverage distribution

Wisconsin Health Coverage 2007



■ Private Insurance ■ Public Coverage □ Self-Insured Employers □ Uninsured all year

* Office of the Commissioner of Insurance, Graph
 ** Legislative Fiscal Bureau memo, January 13, 2009, SB3/AB 15 coverage distribution
 *** Office of the Commissioner of Insurance memo, June 6, 2008

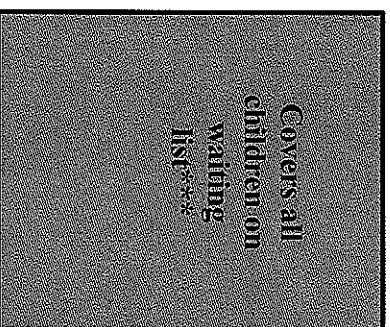
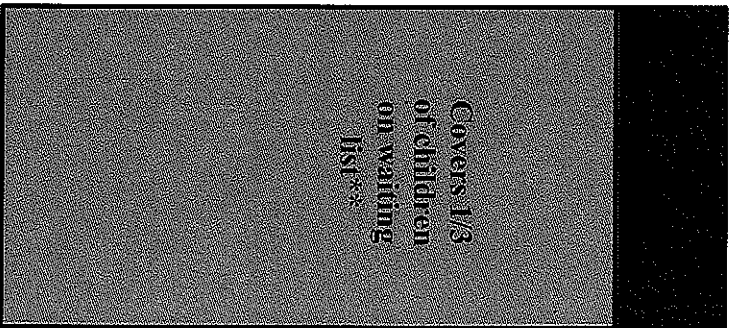
Annual Cost to State/Local Taxpayers (GPR)

\$10,310,000

Local Employees*

State Employees*

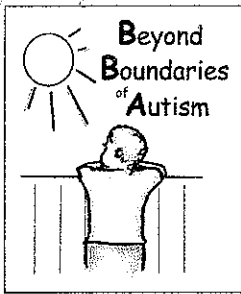
\$5,475,189



SB 3/
AB 15

Newcomer/
Petersen Bill

* Senate Bill 3, Legislative Fiscal Bureau memo, January 27, 2009
** Office of Commissioner of Insurance memo, June 6, 2008
*** February 27, 2008 Legislative Fiscal Bureau memo
**** January 13, 2009 Legislative Fiscal Bureau memo to Kevin Petersen
Incorporate federal matching funds under autism waiver program for Newcomer/Petersen Bill



Beyond Boundaries of Autism
(920) 252-0798
1-866-425-4269 (toll free)
(920) 795-4391 (fax)
PO Box 86, Malone, WI 53049
Skaiser_bba@gwicc.org

A program of
Goodwill NCW
Serving North Central Wisconsin Communities

Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Senator Tim Carpenter (Chair)
Senator Spencer Coggs
Senator Kathleen Vinehout
Senator Dale Schultz
Senator Dan Kapanke

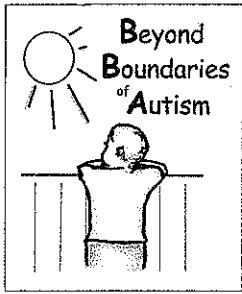
**Public Hearing Senate Bill 3
February 9, 2009**

Relating to: health insurance coverage of treatment for autism spectrum disorders.
By Senators Robson, Sullivan, Hansen, Erpenbach, Wirth, Kreitlow, Jauch, Carpenter, Lehman, Lassa, Miller, Decker, Risser and Taylor; cosponsored by Representatives Hixson, Pasch, Benedict, Berceau, A. Ott, Krusick, Shilling, Turner, Young, Radcliffe, Van Akkeren, Kaufert, Sherman, Pocan, Hraychuck, Schneider, Black, Hubler, Jorgensen, Bernard Schaber, Hilgenberg, Sinicki, Hebl, A. Williams and Steinbrink

Request for expansion of SECTION 9 to Include Licensed Professional Counselors

Submitted by:

Vivian Hazell Program Director/Lead Therapist - Beyond Boundaries of Autism



Beyond Boundaries of Autism
(920) 795-4183
1-866-425-4269 (toll free)
(920) 795-4391 (fax)
PO Box 86, Malone, WI 53049
Skaiser_bba@gwicc.org

A program of **Goodwill** NCW
Serving North Central Wisconsin Communities

Request for expansion of SECTION 9 to Include Licensed Professional Counselors

On behalf of Beyond Boundaries of Autism's families and professionals we are asking you to expand the categories of professionals listed in **SECTION 9** to include Licensed Professional Counselors.

As the bill now reads, the following are listed as authorized providers

1. A psychiatrist, as defined in s. 146.34 (1) (h).
2. A person who practices psychology, as described in s. 455.01 (5).
3. A social worker, as defined in s. 252.15 (1) (er), who is certified or licensed to practice psychotherapy, as defined in s. 457.01 (8m).
4. A paraprofessional working under the supervision of a provider listed under subds. 1. to 3.
5. A professional working under the supervision of an outpatient mental health clinic certified under s. 51.038.
6. A speech language pathologist, as defined in s. 459.20 (4).

As we make this request, we firmly believe that the skills of Wisconsin Licensed Professional Counselors, as described below, certainly justify inclusion in this opportunity.

Wisconsin Department of Regulation & Licensing oversees this professional group and describes their expertise as follows:

Professional counseling means applying a combination of human development, rehabilitation and either psychosocial or psychotherapeutic principles, procedures or services that integrate a wellness, pathology and multicultural model of human behavior in order to assist an individual, couple, family, group of individuals, organization, institution or community to achieve mental, emotional, physical, social, moral, educational, spiritual, vocational or career development and adjustment through the life span of the individual, couple, family, group of individuals, organization, institution or community.

No person may practice professional counseling or use the title "professional counselor", "professional rehabilitation counselor", "vocational rehabilitation counselor", or "rehabilitation counselor" or any similar title unless the person is licensed as a professional counselor by the Professional Counselor Section of the examining board.

We make this recommendation in light of the great work that professionals with this credential have already been doing on behalf of children with autism under the current waiver system. In addition, the state has invested a great deal of quality oversight of this group and can insure the professional standards as set forth in the regulations. Expanding the bill to include this profession not only expands the talent pool that can serve potential families but also opens an avenue of employment for individuals that have already invested in becoming recognized by the state of Wisconsin as trained and appropriate professionals.

Thank you for consideration of this request.

Respectfully Submitted:

Vivian Hazell LPC

Program Director, Beyond Boundaries of Autism



Date: February 9, 2009

To: Chairperson Carpenter, Members of the Senate Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Re: Senate Bill 3, Substitute Amendment 1

The Wisconsin Speech-Language Pathology and Audiology Professional Association (WSHA-P) strongly supports Senate Bill 3 with Senate Substituent Amendment 1, which includes speech-language pathologists as providers of services for individuals diagnosed with autism spectrum disorder. WSHA-P applauds Senator Judy Robson, Representative Kim Hixson, Governor Doyle, legislative co-sponsors, families, and advocacy groups for their dedication to this important issue.

Speech-language pathologists specialize in evaluating and treating infants, children, adolescents, and adults with communication problems. Speech-language pathologists hold masters or doctoral degrees and many have earned national certification through the American Speech-Language-Hearing Association (CCC-SLP or CCC-A).

Speech-language pathologists are independent therapy providers, but they often work as part of a team which may include physicians, audiologists, and psychologists. Speech-language pathologists work in a variety of settings including: hospitals, rehabilitation centers, public and private schools, community clinics, adult day care centers, private practice offices, long-term care facilities, and state and federal government agencies. Depending on the specific work setting Wisconsin requires licensure to practice as a speech-language pathologist from the Department of Regulation and Licensing or the Department of Public Instruction.

Communication problems can range from fluency/stuttering disorders to vocal/voice disorders, speech disorders, or language disorders resulting from a variety of causes. Speech-language pathologists work with a variety of patients including individuals with autism spectrum disorder (ASD), cleft palates, learning and physical disabilities, language delay, hearing loss, and eating, swallowing and communication problems following stroke or a traumatic brain injury or disorder, such as Parkinson's disease.

Speech-language pathologists are trained to evaluate how individuals produce speech, how individuals understand language, and how individuals express themselves. All individuals with ASD are challenged in the area of social communication. Thus, many individuals with ASD have difficulty acquiring the form and content of language and/or augmentative and alternative communication systems, and all have needs in acquiring appropriate social use of communication. Given the nature of autism spectrum disorder it is important that a speech-language pathologist play a critical role in screening, diagnosing, and enhancing the social communication development and quality of life of children, adolescents, and adults with ASD.

The Wisconsin Speech-Language Pathology and Audiology Professional Association appreciates the opportunity to provide information on speech-language pathologists and the important role they play in screening for autism spectrum disorder, and of equal importance in enhancing the lives of individuals with autism spectrum disorder.



Date: February 9, 2009

To: Chairperson Carpenter, Members of the Senate Committee on
Public Health, Senior Issues, Long-Term Care, and Job Creation

Re: Senate Bill 3, Substitute Amendment 1

Easter Seals Southeast Wisconsin touches the lives of nearly 10,000 children and adults with disabilities in our state. We have a seventy-five year history of meeting the needs of children and adults with autism and other developmental disabilities. We believe the proper therapy and treatment for individuals with autism will result not just in important personal gains for these individuals, but also have larger societal effects. For each \$1 we spend on early intervention, \$7 is saved in future support costs in special education and Medicaid waiver funds.

Easter Seals Southeast Wisconsin strongly supports Senate Bill 3 with Substitute Amendment 1 to extend health insurance coverage to individuals diagnosed with an autism spectrum disorder. Easter Seals applauds the efforts of Senator Judy Robson, Representative Kim Hixson, Governor Doyle, legislative co-sponsors, families, and advocacy groups to assure the best, most effective treatments are offered to Wisconsin families living with autism.

Easter Seals strongly supports the inclusion of licensed speech and occupational therapists as independent service providers. These trained professionals have a long history of delivering services through the Birth to 3 Program and other medical treatment. The inclusion of speech and occupational therapists will also help maintain a reasonable cost structure of services.

Easter Seals strongly supports evidenced-based practices like P.L.A.Y. Project that truly fight autism and its effects. P.L.A.Y. Project is currently part of National Institute for Health study in ten Easter Seals affiliates across the United States. P.L.A.Y. Project is based on Dr. Stanley Greenspan's DIR (developmental, individualized and relationship based) philosophy and Floortime. P.L.A.Y increases engagement in children with autism to develop stronger family and social relationships. In addition, it makes the parents the prime-movers in therapy with the support of a trained P.L.A.Y. consultant.

Easter Seals believes parental choice is key to the success of any treatment. The current waiver system has limited treatment options, which may or may not be right for each child or each family, depending on their own circumstances. Senate Bill 3 with Substitute Amendment 1 will allow families to work with their physician to determine the best therapy for their son or daughter.

Easter Seals is eager to begin serving more children with autism and to combat this horrible epidemic that affects 1:150 children and has even higher rates among boys 1:88.

We are committed to providing hope, help and answers to families in Wisconsin living with autism.

INSURANCE TESTIMONY
Monday, February 9, 2009

Glen Sallows and Tamlynn Graupner

About 5 years ago, Wisconsin, along with most other states, experienced budget deficits when the Federal Government reduced block grants to the states. At that time, there were about 1,000 Wisconsin children receiving treatment to reverse the devastating effects of autism. In the midst of this financial difficulty, our Governor and legislature pulled together to create a plan to ensure that these children would continue to receive treatment. All Wisconsinites should be grateful for this decision because by treating children with autism when they are young, almost half can make dramatic improvement. I have had the opportunity to see these children become adolescents, do well in school, enjoy their friends, develop their own interests and become concerned about other children with autism who have not had access to treatment. As we showed in our study, these children were able to achieve average IQ's, language, and social skills thereby saving state money in special education services and long term care expenses. For every dollar spent, Wisconsin saves \$19 dollars down the road.

The waiver went into effect in 2004 and provided continuing funding for treatment at an affordable cost by limiting the number of children who could be treated. Initially this was not a problem, but the incidence of autism is increasing and according to the CDC, has now reached 1 in 150 children, with higher rates for boys. The result for Wisconsin children, was a waiting list to receive services that eventually approached 2 years. This created several problems. Treatment is most

effective when begun prior to age 4 or 5, but with a 2 year wait, more and more children began treatment older than these ages, which some studies have shown is too late to reap the full benefits of treatment. this is thought to be due to decreased brain plasticity as children age beyond the preschool years. The waiting list also resulted in many children being close to mandatory school age when they could finally start treatment, making it impossible for them to receive the number of hours necessary to produce optimal benefit.

Insurance coverage promises to solve many of these problems by providing additional monies. Even though insurance coverage may be available for only a part of those afflicted with autism, this will reduce the waiting list for those without insurance. Children will have access to necessary treatment earlier, allowing more children to achieve optimal outcome, thereby reducing expenses for special education and long term care. Families of these children will be delivered from a lifetime of stress. Finally, it will actually reduce costs for insurance companies because young children who have benefitted from treatment, have fewer injuries, fewer hospitalizations and other health related problems.

Passing this legislation is the right thing to do. It will help thousands of young Wisconsin children and their families. It will reduce school district and state expenses. The increase in premiums is a few dollars a month, and if you or your constituents had a child with autism, passing this legislation will make all of you feel that you are able to do the best possible thing for your child. Your constituents will thank you for looking out for them in their hour of need.

And that is why we all do what we do. We want to help our fellow man because it makes us all feel that the world is a better place.

Statement in favor of Senate Bill 3
February 9, 2009

My name is Eric Anderson, and I'm the President of the Autism Society of Greater Madison. The many people here today are looking to you to bring greater fairness to the citizens of Wisconsin when they utilize their health insurance.

Early diagnosis and treatment of autism is critical to successful outcomes, but proven therapies are often expensive and not covered by insurance in this state. Wisconsin does have a waiver program, but the magnitude of the need overwhelms the available slots, meaning families are left to fend for themselves when timely action is most critical. This forces parents to pay out of pocket and often cripple their financial outlook, or worse, watch their child deteriorate before their eyes. It is unconscionable that any parent should be put in that position.

Beyond the early years, people on the autism spectrum face health concerns throughout their lifespan for which insurance denies them coverage. Let's be clear here: autism is a HEALTH problem. Why on earth should it be singled out and not be covered by HEALTH insurance?

I understand and appreciate the concerns of those who oppose yet another insurance mandate. Passing this bill would increase insurance premiums to private employers. These increased costs are generally a drag on profits or passed along to employees. However, not having a mandate doesn't make health care any cheaper. It just concentrates that cost on an unfortunate few – our most vulnerable citizens. It's also true that with each incremental increase in cost, some will CHOOSE to forego insurance and leave themselves open to the possibility of financial ruin. The key to remember is the whole point behind insurance is risk sharing and risk abatement when an outcome would be catastrophic. This bill allows families confronted with autism to get help in their time of need, the same as families sharing the burden of cancer, diabetes, or other health issues. If others then choose not to abate the potential costs of their health risks, I would say that at least they were given a choice.

When you have a child with autism, the milestones that other parents take for granted are always an open question. From the moment of diagnosis, there's an ongoing question whether our sons or daughters will ever go to college, get married, or hold a steady job, but it doesn't have to be like that. Passing this bill won't eliminate the challenges these families face, but it does remove one of their barriers and provides more equal footing. My son, Carl, will be heading off to college this fall as a National Merit Scholar, and you will see many more such stories if these exceptional children are given the help they need to succeed and become productive citizens.

Wisconsin has a long history of looking out for families, and I know all of you want to do the right thing for all of your constituents. I hope you will choose to correct what the insurance companies have not done and will not do on their own. Thank you.

Eric G. Anderson
601 Blue Ridge Pkwy
Madison, WI 53705
(608) 442-9592 (h)
(608) 663-7526 x305 (w)

Monday, February 9, 2009

Good morning. I am here today to speak in favor of SB3 which would require group insurance plans to cover individuals with autism spectrum disorder (ASD).

I am the mother of Henry Meshke, a seven-year-old boy with autism and cerebral palsy (CP), both developmental disabilities. We are a solidly middle-class family and we purchase the best private insurance available to us through my husband's employer. Our insurance is very expensive but our twin boys were born 12 weeks early and spent 10 weeks in the neonatal intensive care unit so we recognize the importance of good insurance. We gladly pay the premiums so that our children will have the best healthcare available to them if the need arises.

Sadly, our expensive insurance *does not cover a single service related to my son's autism or CP*. When I say they do not cover a single autism- or CP-related service, let me be very clear about what that means -- it means that despite the fact that we pay more than \$5,000 per year for the best insurance available, that insurance will not cover Henry's in-home therapy. It will not cover Henry's physical therapy. It will not cover Henry's occupational therapy. It will not cover Henry's speech therapy. It will not cover anything remotely related to Henry's autism and you would be amazed at what insurance companies can relate to autism.

If we were to pay out of pocket for the many therapies that have been prescribed for Henry, it would cost us *\$8000 or more per month* just for therapy. We love our son and we want what is best for him but we simply cannot afford to spend in excess of \$50,000 per year for the many therapies he needs. As a result, Henry must settle for the therapy we can afford, not the therapy he truly needs.

Many of the parents and professionals you will hear from today will tell you that we need an autism insurance mandate because we need to eliminate the waiting list for early and intensive therapy. They are absolutely right. It is horrifying to know that parents who have recently received the devastating news of their child's autism diagnosis are then being told their child must wait almost two years for treatment.

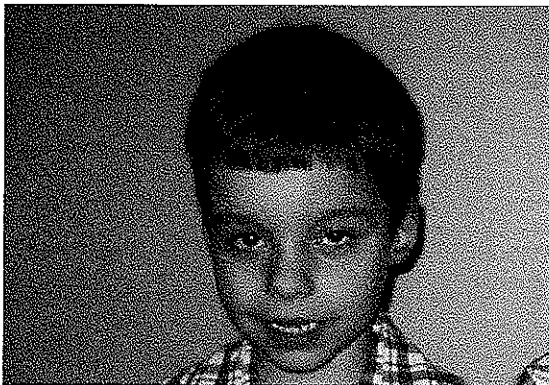
I think we can all agree that if this bill passes, it will help to reduce or even eliminate the current waiting list. This is a good thing. However, as the parents of a child who is almost 8 and who no longer receives intensive services, my husband and I are more concerned with two other aspects of this bill.

The first is the fact that this bill addresses the life-span of individuals with autism. I believe that every parent of a child with autism, no matter how high-functioning, looks into their child's future with fear. Why? Because, to date, the primary focus of autism programs here in Wisconsin has been very young children. We seem to have forgotten that these very young children quickly become teens and eventually adults. And as they age, their needs do not disappear, they simply change. We are here today because, regardless of age, not a single one of the 35,000 individuals with autism in the State of Wisconsin receives group insurance reimbursement for their autism-related treatment. Furthermore, even if every one of those

developmentally disabled citizens as they do to everyone else. For our family and other families living with autism, the choice is clear. I hope the same is true for you.

I thank you for your time. I have provided you with a copy of my comments and contact information. I encourage you to contact me if I can answer any questions, clarify any comments or offer you additional insights into the challenges and joys of loving and raising a child with autism.

Lynn Meshke
Mother to Henry Meshke (age 7), autism and CP
1946 Copper Top Way
DePere, WI 54115
920.336.9969
Meshke@sbcglobal.net



This is our son Henry. He is 7-years-old and has both autism and cerebral palsy. Henry is non-verbal and walks with a walker but he has demonstrated that he is very smart. Despite not speaking, he is quite charming and has a great sense of humor. We would ask that you think about Henry and others like him when you consider this bill. Please remember that although he is 7 now, he will someday be a grown man with significant needs who will benefit from an autism insurance bill that protects his rights throughout life.

**Senate Committee on Public Health, Senior Issues,
Long-Term Care, and Job Creation**

Testimony in Support of SB-3

Stephen F. Seaman, Ph.D., M.S.
2/9/2009

Mr. Chairman and members of the committee:

Thank you for the opportunity to speak on behalf of SB-3, which would require health insurance policies to cover the cost of treatment of Autism, Asperger's Syndrome and Pervasive Development Disorder Not Otherwise Specified. These three disorders are often referred to as Autism Spectrum Disorders (ASD) as they share many common characteristics. A recent study estimated the prevalence of ASD as approximately 6.0 to 6.5 per 1000 people.

As a psychologist in practice for almost 30 years, I have had the occasion to treat many patients with ASD. They represent a broad range of functioning from college graduates to learning impaired high school dropouts; from married individuals to those with severely impaired social functioning; from those with successful careers to those who have never been able to work; from those who generally function within society to those who are unable to live independently or are even incarcerated due to severe behavioral difficulties that have led to legal offenses. This range is consistent with the range that is generally seen in the ASD population. What this range of people has in common is an impairment of social interaction and communication, along with restricted activities and interests. Essentially, there is an impairment of the ability to perceive and interpret subtle or nonverbal social cues that most of us rely on in our interactions with others. Most of us intuitively understand the emotional state of those we interact with, and are able to recognize their response to us. This ability is impaired for people with ASD.

While I cannot say with certainty why ASD has been excluded from coverage by many insurance policies, there may be several reasons. First, while the causes of the disorder are complex and varied, in most cases there is a significant neurological component. Therefore, it has sometimes been viewed as similar to mental retardation, Parkinson's Disease and other neurological conditions that are not amenable to psychological or psychiatric treatment. Second, because each person with an ASD has a unique set of strengths and weaknesses, treatment is best individualized to the needs of that person, making systematic research on the efficacy of treatment more difficult. Third, when

people with an ASD enter treatment, it is usually for treatment of another problem (depression, anxiety, loneliness, anger problems, behavioral problems, job loss). Even though the ASD may be a causal basis for the presenting problem, oftentimes the treatment focuses on the presenting issue, and once that has improved treatment ends.

Cure or remission of symptoms as we might expect in the treatment of depression, anxiety, phobias, panic attack or even bipolar disorder or schizophrenia, is generally not possible for Autism Spectrum Disorders. Nonetheless, some of my most rewarding experiences as a psychologist have been in treating these types of patients, and some of the most important long term impact on functioning has occurred. It is for this reason that I support this bill. The goal of treatment is initially to help both patients and important people in their lives to label and understand what is "wrong." Typically patients and their families recognize that they are "different", or "don't fit in", but don't understand why. The next part of therapy is concrete social skills training, so that the patient can learn a set of "rules" about how to behave and understand the behaviors of others in order to function better in normal social settings, including work and school.

Look Me in the Eye: My Life with Asperger's by John Elder Robison is a fascinating personal discussion of this process. The title reflects one of the skills the author needed to learn: to look the other person in the eye when speaking with them, an innate instinct most of us have, but was missing in him (and many others with ASD). By learning a set of rules or procedures, patients with ASDs can function much more effectively in many aspects of their lives.

Aside from improved quality of life for individuals with Autism, Asperger's or a Pervasive Developmental Disorder, effective treatment is a benefit to the society at large. The incidence of secondary psychiatric disorders which would require treatment (such as depression, anxiety or profound loneliness) is reduced. Behavioral or anger control issues, which can result in job loss, police involvement or incarceration, will be reduced. Finally, some people with ASDs, along with areas of deficit, have areas of unique ability and talent. As a society we can best benefit from the unique contribution that individual might have to offer, if they have learned to manage the areas of deficit.

February 9, 2009

Good morning. My name is Peggy Helm-Quest and I am the mother of two children and serve on the Autism Society of Wisconsin (ASW) Board. My oldest child Nate is 14 and was diagnosed with Asperger's Syndrome/Autism at the age of 4. As a state employee (I work for the Division of Public Health as a consultant), I have had to change insurance providers 4 times due to continual denials regarding Nate's health care after his diagnosis of Asperger's was put on his health record - only to default to the insurance provider I currently maintain, because there are no other insurance provider choices left to chose from.

When Nate was 3, we began our quest to seek a psychological assessment to determine why Nate was exhibiting violent tantrums lasting hours on end. Asperger's syndrome is not a more milder form of Autism, it's presentation is just different and requires a different skill-set to address, manage, and cope with the tantrums, rages, meltdowns, and anxiety when the person with Asperger's is unable to communicate their frustrations and sensory overload.

Getting an insurance authorization to see a Psychologist was denied, so we paid out-of-pocket for an initial evaluation and follow-up consultation. We left her office with an apology and a diagnosis. Being in the health field, I sought a second opinion to see a Developmental Pediatrician. That was also denied by my insurance. We continued to appeal for over a 1 year period, meanwhile his diagnosis questioned any insurance support for even basic health services, so we changed insurance providers.

Our Pediatrician helped secure 1 (one) Developmental Pediatrician visit which confirmed the diagnosis at age 4. The Developmental Pediatrician referred Nate to a Neuro-Psychologist to help further define his disorder. After being put on over a 1 (one) year waiting list, the insurance company blocked the appointment on the day of the appointment, citing coverage denied. At this point, Nate was able to read and had a vocabulary of a 5th grader - however he was not toilet trained, could not play with other children, and experienced huge behavior challenges. We applied to Medicaid, but was denied because Nate did not meet "level of care".

Because of the lack of health insurance coverage for Nate's autism related health needs, his quality of life has been severely impacted. As an example, Nate has been in 9 (nine) different school placements in 10 (ten) years, suffers from post traumatic stress disorder (PTSD), and his anxiety and depression prevents him from age appropriate social interactions.

Fast forward to today - Nate is a freshman in high school, he has been denied necessary health care since the age of 4 at an intensity, frequency, and duration to address his PTSD, anxiety, depression, and sensory defensiveness issues - including group therapy, OT, PT, and dental specialty care. Because of his diagnosis, Nate has been discriminated against in accessing psychological cognitive behavioral therapy as anxiety and depression are co-morbidities of autism and autism is not a covered diagnosis - even though others with anxiety and depression without an autism diagnosis would be afforded psychological therapy to address their needs.

The continual lifelong healthcare needs of children like Nate are unknown, however if children are to become productive citizens such as Nate is capable of doing (he would

like to be a pilot) accessing appropriate services immediately upon diagnosis is imperative, that also includes lifetime health benefits with a lifespan approach to healthcare.

Thank you for your time and supportive action to address healthcare coverage, healthcare access, and the healthcare needs of people with autism.

Peggy Helm-Quest
167 Church St
Merrimac, WI 53561
608-493-4131

Nate Helm-Quest
Age 14





Wisconsin

**Statement Before the
Senate Committee on Public Health, Senior Issues, Long Term Care
and Job Creation**

By

**Bill G. Smith
State Director
National Federation of Independent Business
Wisconsin Chapter**

**Monday, February 9, 2009
Senate Bill 3**

Mr. Chairman and members of the Committee, thank you for allowing me to make a brief statement on behalf of small and independent business.

I am not participating in today's hearing to diminish or deny the cost and anguish that comes with the treatment of an autistic child.

However, contrary to the goals of those who favor this legislation, quite the opposite of expanding health insurance coverage to cover the treatments for autistic children could be the net result.

A government mandate to expand insurance coverage has little to do with big insurance companies.

They will sell the coverage. The question is whether small business will be able to afford to buy it.

According to Mercer Health and Benefits, health insurance costs in Wisconsin are already 23% above the national average. Only about 41% of Wisconsin small business employers offer health insurance to their employees, and that percentage is decreasing every year as health insurance plans become less affordable and economic challenges more formidable. Health insurance costs increase for many reasons, but there is no question government mandated coverage's contribute to less coverage or no coverage for many small business owners and their workers.

Testimony by Bill G. Smith, NFIB – continued
Senate Committee on Public Health, Senior Issues, Long Term Care and Job Creation
Page Two

I know the proponents of this legislation argue the impact on cost is minimal. However, studies show a mere 1 percent increase in the cost of a health insurance plan equals over \$36 million in premium costs for those who purchase group health insurance, primarily small employers.

This mandate, at best, Mr. Chairman, will affect only about 26% of Wisconsin citizens in the commercially insured market. Obviously, passage of this legislation will not adequately or efficiently address the concerns of the authors of the bill. In fact, passage of this bill may result in less coverage or even no coverage - but passage will clearly result in higher insurance costs for small business.

Small business owners believe they should have the freedom to structure their plans based on affordability and the needs of their workforce, without mandates by government.

These children need and deserve treatment. However, I urge members of the Committee to examine all the options, and to resist the easy mandate response to this very serious issue. A response that, in the long term, will fail.

It is on behalf of these small business employers that I request a vote against passage of SB 3.

February 9, 2009

My name is Renee Tarnutzer and I am from Janesville. I always thought my son, Alex, would have the same opportunities as every other child – no matter what. Even last November, when we heard the words “Alex has Autism,” my husband and I thought to ourselves, “OK. He’s been through four daycares. We know he’s been struggling. We can manage this. We’ll get him the help he needs and he’ll be OK.” Never in a million years did I think that simply trying to get Alex the help he needs would be one of the biggest battles of my life.

First, we tried to get insurance coverage for the diagnostic appointment and it was denied – a financial blow of five hundred and fifty dollars. Then came the evaluations – also not covered by insurance. We turned to our school district for help. Although they determined his autism will have a “negative impact on his educational performance,” he does not qualify under state guidelines for help. In April we are supposed to have another appointment with the diagnosing pediatrician but we may have to cancel it so that we can put the five hundred dollars toward other therapy sessions that might be more beneficial. Three months after the diagnosis and we are faced with the fact that we are alone financially in this fight.

Alex needs help from an occupational therapist for fine motor and sensory processing and from a psychologist for social skills, rigidity, transitions and aggression. Since he doesn’t qualify for help from the school or for the autism waiver through the state, we are faced with choosing from the therapies that the doctors recommend because we can’t afford all of them. Any help that he gets will be out of our pocket – a very expensive journey.

Just imagine knowing that there is help for your child but you cannot provide it for him financially. Imagine the guilt you would feel. And there are many kids out there who need much more therapy than Alex does – and at a much higher price tag.

Alex has high functioning autism and it is treatable – if he gets the help he needs NOW. Unfortunately, Alex will only get as much help as we can financially afford to give him because he does not qualify for help from the outside – not from insurance, not from the autism waiver and not from the school district. Alex, and countless others like him, is falling through the cracks. With the proper treatment, Alex will be a higher functioning adult someday. Without the help of our insurance, though, we will stretch our dollars as far as we can but it still will not help him reach his highest potential.

This is a battle like no other. You already know the facts and figures about Autism. You don’t need to hear them again from me. The fact is that these are our kids. This world is already difficult enough for them as it is. We don’t need to make it more difficult. No child, not mine, not yours, not any child in this state, should be deprived of getting the help that they need for a medical condition. You have the power to change their lives. You need to do the right thing. Pass this bill. Let these kids fight the good fight and help them conquer this battle with Autism.



Renee Tarnutzer
3511 Kingsbridge Drive
Janesville, WI 53546
608.743.1401
renee@lego-man.com